Extract from the book *Supporting Positive Behaviour in Intellectual Disabilities & Autism: Practical Strategies for Working with Challenging Behaviour,* to be published in November 2019 by Jessica Kingsley

10. Afterword: What I Think When I Talk About Autism

There could be other books. (Think of this less a threat, more a hopeful promise.) A book focussed on positive behaviour support and practice leadership, for example, or one concerning how we might easily mend meltdowns without using physical interventions or dehumanising responses (this must include how we *feel* not merely think about facing challenging behaviour.)

These *possible* books might also explicitly consider autism. Because even in this book about challenging behaviour readers will have noticed an elephant in my room, namely, my infrequent use of the word autism: this is inevitable due to the fact that in our family autism is personal, and as the great Canadian poet Alden Nowlam noted, writing the personal is about the most meaningful thing a human can share with another. It takes gumption and authority.

Naturally this book mentions approaches to challenging behaviour that are applicable in autism because the approaches are (hopefully) *human* friendly: they apply to people, because good behaviour support is much like gravity: no human is immune (no matter what they choose to believe). Humans are a diverse spectrum[13] of a species, with both nuanced and significant identities and capacities: we share certain characteristics, for example, our ability to learn, to feel, to share, to belong,

[13] this suggests linearity- from 'very' to 'little', from 'tall' to 'short', for example, as if humans can be categorised so very simply. The reality is much different. Spectrum doesn't have to mean a line, it can imply a continuum, such as in this case. Multi-axial imagery works better, I think, and avoids a sense we are each associated with quantifiable definitions and thus fixed for life. Saying an autistic person is at one point of a spectrum diminishes our capacity to understand the variations amongst people at 'the same place' on the spectrum, and so limits our understanding.

and their opposites. We have far more in common than some people would have you believe.

Wherever I go to talk or work regarding challenging behaviour, autism is mentioned. In response to *anything* I say concerning behaviour someone usually adds, 'In principle… but in autism?' One reason I struggle to respond is because it may be we are speaking at cross-purposes when discussing autism, it may be too personal, and it may be words have failed me: how can I speak of remarkable things, such as the variegated patterns of humanity, its diasporas of identities, whilst also suggesting we all have much in common, without offending those being or seeking unique identities?

To side-step miscommunication I have learned to suggest that if the principles of good behaviour support are truly person-centred in their application, then elements can be applied to support individuals regardless of diagnosis, identity or attribute. Good practitioners are sensitive to individual preferences whilst using common principles of person-centred functional assessment and person-centred behavioural support. Person-centred support looks at individuals as whole people rather than diagnostic categories, even if diagnostic categories can teach us about *likely* commonalities.

Autism is a label that is applied to a diverse group of people sharing some commonalities, and it may turn out autism isn't one thing but many: autism is one thread of humanity that is present from childhood and continues throughout the

person's life. We cannot cure autism (and there's a debate to be had about even assuming we should. Think of the implications of curing *any* part of humanity. Who judges, who decides, and who carries out such a final solution? Evolution seems to know it is doing in producing such differences amongst humans). Because autism – in its current definition – is a tall, wide, deep, and many-coloured splendid thing, it is easy to spot these commonalities in some, more difficult due to its nuanced appearance in others.

It doesn't help that some diagnostic methods seem biased toward obvious behavioural or cognitive signs that are good often for males and not so great often for females: both are equal but different in terms of autism assessment. And then there are those who identify as neither – are diagnostic tools keeping up? (Only if our *recognition* of the need for more subtle ways to comprehend each other does.) The end result is that whilst plenty of young children are diagnosed early, many are not. There are times people are not diagnosed until some way through their lives, and some, not at all. Should every autistic individual be identified? Being diagnosed *should* enable support to be tailored, and the individual to have a foundation from which to build their identities, and it certainly may help others to understand a little more about the individual. We diagnose through observing behaviour. This is like commenting on the quality of the meal as we stand outside a restaurant.

As I write, people living in one county of the UK face a waiting list for a child's autism assessment through statutory services of thirteen months. That's pretty shoddy and inept, especially as it impacts the wellbeing not only of the child, but of families. Further, once a diagnosis is received the experiences of gaining insightful support are

not uniform across the UK. It turns out there are deserts and forests across the land – of provision, expertise, and vision. The autistic diagnosis is only the first hurdle in a steeplechase across such a landscape: the dangerous water jump on the second lap is getting information & support following that diagnosis.

Traditionally we say autism is present when we observe certain patterns of behaviour. Everyone we meet thinks they know about autism, even if it's rudimentary or stereotypes derived from the television show *Big Bang Theory* or the film *Mary & Max.* No media representation can truly reflect people, only small bits of their experiences. Autism 'behaviours' vary depending on mental capacity, age, skills and opportunities offered. And it depends how much people trust the person assessing them.

One commonality across 'the autisms' is "empathic capacity" (Delfos, 2005, p.84) – that is, the ease with which the individual relates to others. You see, one neurotribe[14] thinks the autistic neurotribe struggles with empathy, which is a bit rich given the track record of a lack of understanding common *across* neurotribes (Silberman, 2015). So autistic people are considered to lack empathy, which I'm sure you'll agree, shows a distinct lack of empathy, a problem with generalisation, and a lack of imagination, by those pointing accusing fingers. This is called the double-empathy problem (Milton, 2012): both autistic people and neurotypical struggle to empathise and understand one another.

[14] Let's imagine humanity is made up of different groups who share ways of thinking and experience the world – think of a neurotribe as a community of experience, each sharing commonalities & preferences. People can each belong to many different tribes over their lives, I suspect. We can craft ourselves.

Another thing people speak of as being a commonality in autism is an often *uneven* set of abilities: if we were to graph the different skills of children or adults, the diagram would seem a little 'spiky': great at this, not so great at that. An individual may be able to debate moral relativism but have trouble safely crossing a road. Such a profile may be extremely spiky in autistic individuals but to a lesser or greater degree the same thing is found in many humans. In autism, it's the *significance* of such differentials that matters.

We may all experience anxiety about social situations to some degree, but what is a lukewarm unpleasantness for some is a roaring broiling pot of horror for others. After a busy day filled with novel social situations, neurotypicals might relax in the peace and quiet of solitude, but many autistic people might collapse from exhaustion at trying to translate what the hell has occurred and what it means to be them.

Similarly, we may each have certain sensory preferences, but autistic people may not have an option but to feel their teeth are electrified when eating certain foods or textures. Neurotypicals might dislike certain smells or sounds, but an autistic person is hardwired to find them physically repulsive. Again, it's a matter of the magnitude.

For more than twenty years we've spoken of autism as one umbrella term to describe a *spectrum* of different *presentations*. We know each of these presentations *tend* to have characteristics justifying our use of the term autistic: these of course include differences from the abilities shown by others in terms of communication, social interactions and patterns of behaviour including cognitive behaviours, but they also very much seem to incorporate sensory processing. These have become known, for

good or ill, as the *triad of impairments.* (There go the neurotribes again, labelling a difference as an impairment.) Whether someone is intellectually gifted and eloquent, or has no speech and has severe IDD, we might see similar characteristics or commonalities through their behaviour.

Here's a conundrum: if the autistic child learns to behave in ways that are not considered 'autistic', are they autistic any longer? That is the claim of some behaviourists: to teach behaviours that mask or replace 'autistic' behaviours so well the child might not be considered autistic based on our assessment of autism as a collection of observable behaviours. But autism is so much *more* than observable behaviour: it is a way of thinking and experiencing the world (i.e., Grandin, 1995; Jackson, 2002). Autism is a term that encompasses people with profound IDD, Nobel Prize Winners, and everyone inbetween.

Whilst we might once have said the 'spectrum' of autism consisted of three distinct 'groups', today we think this is less absolute. Some find the 'three group' spectrum helpful in terms of identity:

- Classic (or Kanner's) Autism
- Asperger's Syndrome
- Atypical Autism, sometimes confounded with pervasive developmental disorders.

Each 'type' has unique indicators though a person who has been diagnosed with one of these might appear little different to a person with a another 'type' of autism, especially for support purposes (Wing, 1998). Therefore some ways of diagnosing

autism have eliminated these three groups, combining them into a single 'autism'. This means that when we hear the word autistic, we might be speaking of divergent individuals: 'autistic' can cover a multitude of spiky profiles. Autistic people (like all humans) have variable attributes whilst also having commonalities. (People keep tinkering with the definitions, but the people being spoken of remain, and the experiences of their lives go on.)

Not all autistic people share the gifts outlined in the table below, as not all those who are not autistic (neurotypicals) do, but Vermeulen (2001) provides a short and handy guide to what we might expect to encounter.

Gifts of autistic and non-autistic people	
Autistic People	Non-Autistic People
Literal Interpretation of Information	Contextual Interpretation (spirit of things)
Analytic Thinking (Not so Integrated)	Integrated Thinking (Not so Analytical)
Eye for Details (Misses Big Picture)	Eye for Big Picture (Misses Detail)
Concrete Things & Facts (Vagueness not Welcome)	Abstract Things & Vague Ideas (Not So Good At Facts, Questions Literalism)
Rule Following	Living Between the Rules
Objectivity ('Mind Blindness')	Subjectivity ('Theory of Mind')
Realism ('What Is')	Surrealism ('What Is Not')
Perfectionism ('Binary- Good or Bad')	Flexibility ('Shades of Goodness')
Absolutes	Relativism
Calculations	Intuitive Feelings

Giftedness (adapted from Vermeulen, 2001, p.132)

Vermeulen might be the first to acknowledge just how many exceptions we each know. And that's why I'm so cautious about talking about autism; the older I get the less certain I am of the ideas I grew up with.

(When I was a child we had *nine* planets (poor Pluto got dumped from the club – if they can exclude a heavenly body, what chance have *I* got?) Also, in the good old days, I only had to contend with three dinosaurs – the hungry one with tiny paws, the veggie big one with that cool sail on its back, and the huge one with the massive tail stomping early humans. Now there are thousands of dinosaurs, and early humans weren't even around).

And that is why research goes on, to help us learn more evidenced accounts of why things are as they appear. There are always new things to discover, and older lessons to remember. Ructions are inevitable.

We are some way from finding a simple and elegant explanation of what causes autism – perhaps there are, as Uta Frith suggests, long causal chains comprising many factors (Frith, 2003) that lead to a myriad of neurological changes that may be profound or mild in their effect on the person. Regardless of causes and processes, whether autism is one thing or many, the outcomes can be profound: *"My way of functioning has also meant that occasionally I find it difficult to show understanding of other people. I can't help thinking that people are rather pathetic in their need to be loved by everyone; that they are naïve not to be able to disregard their own feelings, to keep things and people apart, even. But usually I just feel sorry for them when they can't… But now I've realised I needn't be sorry for them, because they do*

gain something from what seems so troublesome to me. They think it's good to get so involved, and that people really are concerned about others. They perhaps even want to be drawn into conflicts and then complain about it, because they think its just part of life. They don't always mean what they say: they can say something is upsetting when in fact they like it," (Gerland, 1997, p.245-246).

What I think when I talk about autism is that my fragmentary account is only one pixel of a picture. My pixel has been drawn from memory, personal experience, practice and current research, and my pixel is being refreshed every moment. The *other* thing I think when I talk to others about autism is that for each account I hear people espouse I try to remain acutely aware of exceptions. When a neurotypical tells me autistic people do this or do that, I think the following: *neurotypicals are so obsessed with their limited interests in suggesting the autistic mind isn't good at empathy and communication, they overlook their own deficits of theory of mind.*

But perhaps I am just lacking empathy here.

A Two Way Street? Theory of Mind

When people attribute thoughts and feelings to others, and display an appropriate emotional reaction,[15] we assume they empathise. Those who do not empathise in

[15] and of course the question here is who defines *appropriate* in a given situation. And if I don't respond how people think I should, will their view of me be 'he's just tired and so a little disinterested', or will they view me as pathologically 'odd' or 'indifferent' to their (often) quite dull self-obsessions, and so not answer my emails in the future. This is why I often will say 'oh my goodness, that's terrible/great' (select as required) to people emoting, even if I have no idea who they are. Being empathic, like being altruistic, is beneficial (and so a little selfish) for the person being empathic and altruistic. And yet we accuse autistics for an apparent 'what's in it for me?' or 'who are you?' indifference. Go figure.

customary manner are often viewed as indifferent. Empathising requires (to some degree) the skill known as "mind reading", or theory of mind. This was at the heart of research into autism, because often autistic people are reported to struggle with understanding other people do not think or feel the same as them (Frith, 2003). Put simply, having a well-developed 'theory of mind' suggests we attribute to people we meet thoughts and feelings other than our own: another person can know or feel things we do not; they may not know or feel what we know or feel. (The happy result of this means neurotypicals[16] can easily lie to people- this is both an evolutionary boon *and* a moral problem.) Evidence suggests some autistic children are delayed in developing 'theory of mind' or it is learned later. Brain imagining suggests reduced activation of some areas when autistic people face theory-of-mind tasks. This 'lack' of theory-of-mind is often referred to as 'mind-blindness'. (But we know there are degrees of visual ability, too.)

Many neurotypical children have a well developed theory-of-mind (attributing thoughts & emotions to others becomes 'intuitive' early in their lives) that contributes to apparently 'seamless' social exchanges, whereas autistic children may have to work out the rules of social interactions logically. Increase the complexity of social interactions, however, and not 'intuitively' being skilled at 'mind-reading' is a fundamental challenge. (One way to think of this is that autistic children sometimes say what they see *regardless* of the feelings of others, whereas neurological children know the social benefits of lying about how Grandfather smells[17] when he comes in from smoking his pipe in the back garden.)

[16] i.e., people who are not autistic
[17] i.e., really bad. I mean utterly disgusting. But not to him. He smells of cherry wood to him.

Elizabeth Sheppard and colleagues questioned some of the rudimentary tropes still to be found concerning autism. They started from the existing evidence that autistic people respond differently to non-autistic people regarding social situations – autistic people have difficulties 'reading' the minds (or 'mental states' of others). But they wished to explore its opposite: how good are non-autistic people at 'reading' the minds of autistic people? It turns out not very good at all. Autistic people have equally expressive faces as neurotypicals, the study showed, but neurotypicals struggled to interpret the thinking of autistic people. The authors suggest autistic people experience a double-jeopardy: they start from a position of struggling to interpret the thinking of others who are struggling to interpret their thinking (Sheppard, *et al.,* 2016). It turns out theory-of-mind is not fussy about where it finds it hard to find shelter.

And what I think of when I speak about autism, is 'And so?' because seamless social exchanges are perhaps not as common as we like to think, and intuitive is just another way to say 'learned then forgotten we learned'. In so-called neurotypical seamless exchanges contain a degree of performance, a pinch of assumption, a sprinkling of recognising how we appear is perhaps more important that what we truly are. Autistic people may use more deductive approaches to working out others.

Uta Frith gives a telling example of the consequences of a not-fully developed theory-of-mind: *"Josef took a trinket from a whole box of things by lucky dip and put it in a cup. He then ostentatiously let the child look inside, making it clear all the time that I (who sat at the other end of the table) was not allowed to look inside. He verified that this was understood by asking: 'Did you see what was in the cup?' and 'Did Uta see*

what was in the cup?' Now the critical questions were: 'Do you know what is in the cup?' and 'Does Uta know?' Astonishingly half of the autistic children who were tested, said, 'Yes, Uta knows [what is in the cup],' when I had not seen the object and could not have known. All were at a mental age above that at which normal children could easily give the right answer" (Frith, 2003, p.213).

Note *half* of autistic children passed this simple test. This hypothetico-deductive method is more protracted than for a non-autistic child. Autistic people may be obliged to comprehend the benefits of ascribing to others independent thoughts and feelings *the slow way*. Make a social situation more complex and the 'processing lag' (or interpretation of what is expected) will take longer. For autistic people, understanding neurotypicals is hard and confounding work. Sometimes, it simply may not be worth the effort, and best stick to what they know.

Theory-of-mind is a description of an issue rather than an explanation (Bowler, 2007). Social interactions are more complex than simply saying someone passes through intuitive or hypothetico-deductive methods to arrive at the idea others have their own knowledge or feelings. Some who see more fundamental issues impacting on people dispute theory-of-mind as an explanation of autism, but it *is* helpful in understanding what we might otherwise perceive as callous indifference in some humans. My own view, drawn from long personal experience, is this is far from a unique indicator of autism. Just watch the news.

(As presented throughout this book, human interactions are often communicative and a two-way street. Some communications are mutually beneficial – for example,

interpreting a particular challenging behaviour as having a message - but this is not the case for all interactions. Neurotypicals are profoundly gifted at not telling the truth and manipulating others in order to accrue benefits. Neurotypicals seldom accuse themselves of pathological indifference to the welfare of others. (They simply accuse others.) Neurotypicals are skilled at 'morally disengaging' (or 'turning down' their own theory-of-mind) when encountering people in distress or people who need to do things that benefit the neurotypical. It is at best merely ironic that those considered normal – those who hold the power to label other humans as not normal - are often the cruellest of the neurotribes on our planet.)

If theory-of-mind holds as one of the central issues for an autistic person, imagine the potential impact on communication and social interactions: one might appear uninterested in the welfare of others, unwilling to communicate when from the perspective of the autistic person what the other person is saying is boring or not relevant. It can be argued then that theory-of-mind deficits are not unique to autistic people or other neurological conditions (we know people profoundly impacted by 'schizophrenia' likewise struggle with theory-of-mind tests) – but rather a matter of the significance of the impact. We've *all* got spiky profiles of skills to some degree, and we each struggle to understand others. We're all flawed. None of us can look in the mirror and proclaim ourselves perfect.

Neurotypicals communicate in a code called language that is often illogical but that they assume is *de rigueur*: the reality is neurotypicals often don't mean what they say or say what they mean. Neurotypicals survive by assuming contexts are as relevant to

meaning as actual words: autistic people are often left bemused and alone in such exchanges (Wheelwright, 2007).

It could be the autistic child interprets literally what the neurologically typical child 'knows' alludes to something else when hearing the phrases, "give me your hand" or "let us toast the bride". The autistic child may decode these startling words whereas a neurotypical child may 'know' what is intended.

What I think when I talk about autism is that I'm talking about humans, and whatever neurotribe a person is part of, there is *"a challenge of mutual understanding and a process of translation… Failure of understanding can go both ways. We have no idea what it is to see the world through the eyes of autism"* (Happé, 2001, p.9). Vermeulen notes,*"resistance to changing our ideas about autism is sometimes greater than that seen in people with autism. So noted a young man with autism, too, and the way he formulates it is clear proof of two facts: (1) people with autism can have a driver's licence and (2) people with autism do have a sense of humour: 'In May of 1989 I drove 1,200 miles to attend to 10th annual TEACCH conference, where I learned that autistic people can't drive…'"* (Vermeulen, 2001, p.24-25).

Gerland provides another example of how neurotypicals' own theory-of-mind abilities might be overstated: *"...if it looked like defiance, it had to be defiance. They measured me according to the way they measured themselves. They started with the premise that I was the same as they were, and if I wasn't*

Failing to understand one another is not a deficit owned by one neurotribe. Are neurotypicals so reliable that theirs is the only standpoint that counts? Do you think neurotypicals are *correct* to label autism a disability? Are neurotypicals so developmentally delayed they fail to understand the benefits of neurodiversity? This is what I think when I talk about autism: how come you work with autistic kids or adults and don't learn from them, that you remain unchanged when meeting other humans?

Identities are powerful forms of self-expression and being. Identities when imposed may become a defining (and perhaps limiting) characteristic justifying exclusion; when self-crafted, identities are a tool for liberation and inclusion.

So these are some of the things I think when I'm asked to talk about autism. I see fundamental differences in how the world is encountered because how we touch the universe and think about it is largely achieved through delicate neurology: our nervous systems join us to the physical world, the sensory world and the social world of ideas, memes, dogmas and experience. Tweak the neurology, tweak the lived experience: different neurologies are valid, I'd suggest.

None of us own the truth or have the right to compare one spiky person against another, and claim one is normal, one is not. Why, doing so would be like my kids standing in the garden at night fighting over which of the flakes of snow they've caught is *the* most beautiful.

They know ‘each one is beautiful’, and they get the bigger picture, too, that arguing over flakes of snow distracts us from stopping in amazement at just how utterly remarkable it is to be alive, standing at night in a garden beneath falling snow. They also know in the morning each tiny flake of snow has contributed to a reshaping of the once familiar world.

We know snow is just bits of chemistry. And there’s wonder in that. But there’s also wonder in what flakes of snow falling from a dark sky taste, feel and look like, the ideas they trigger in our heads, the patterns they create when combining to carpet the garden. My children *all* know this, no matter who they are, no matter their gifts.